

**STRATEGIC
OBJECTIVE**

7

Improve the Quality of Life for Cancer Patients, Survivors, and Their Families

We will support the development and dissemination of interventions to reduce the adverse effects of cancer diagnosis and treatment and improve health-related outcomes for cancer patients, survivors, and their families.

NCI's Vision to eliminate the suffering and death due to cancer supports the interests of the nearly ten million cancer survivors in the United States today. While the ultimate goal of eliminating cancer entirely continues to be our long-term commitment, the capacity to dramatically reduce the suffering caused by cancer is within our immediate grasp. This is in keeping with the Department of Health and Human Services Healthy People 2010 goal of five-year survival for 70 percent of those diagnosed with cancer. Advances in our ability to detect, treat, and support cancer patients have turned this disease into one that is chronic or readily managed for many and curable for increasing numbers.

We are learning more about the nature and scope of problems encountered by cancer survivors. Research is enabling us to better predict who is at risk for adverse health outcomes and to develop innovative interventions for treatment effects such as fatigue, memory difficulties, mucositis, nausea, and pain. Through clinical trials, investigators are trying to identify genes, proteins, or other biological markers associated with a patient's response to treatment. The ability to use genetic signatures to recognize tumors that are likely to recur after treatment could allow doctors to tailor treatment plans accordingly, sparing patients with good prognoses unnecessary therapy.

Partnering with others will assure appropriate follow-up care and increase adherence to optimal health behaviors among survivors. Understanding the impact of cancer on family members of patients and survivors—many of whom are themselves at increased risk for cancer due to shared cancer-causing genes, lifestyles, or toxic exposures—is also essential to achieving our Vision. As cancer care migrates to the outpatient setting, the economic, physical, and emotional burden on family members is increasing. Research must equip healthcare teams to better prepare family caregivers to manage patients at home while sustaining their own emotional and physical health.

STRATEGY 7.1—Expand research efforts to understand biologic, physical, psychological, and social mechanisms and their interactions that affect a cancer patient’s response to disease, treatment, and recovery.

While research documenting the impact of cancer on patient and survivor health-related outcomes continues to grow, much remains to be learned about who may be at risk for specific disease- or treatment-related sequelae, what factors moderate or mediate risk, and the interaction of these on patient health. Increased understanding of how cancer patients respond to disease, treatment, and recovery will enable the development of interventions to improve quality of life during and after cancer treatment. NCI will:

- > Strengthen behavioral and epidemiologic studies of cancer and its treatment among patients and survivors examining both negative and positive physiologic and psychosocial effects and their correlates.
- > Support research on the biologic and physiologic mechanisms involved in adverse chronic and late effects of both current and new cancer treatments. Using molecular epidemiological research, we will seek to identify the genetic and/or phenotypic markers of susceptibility to treatment-related adverse effects and gene-environment interactions.
- > Promote the incorporation of quality-of-life endpoints within NCI-supported clinical trials and enhance the capacity for long-term follow-up of survivor cohorts.
- > Collaborate with others to synthesize the research on the role of sociocultural, behavioral, emotional, and spiritual factors in survivor and family outcomes and survivors’ adoption of appropriate surveillance and health maintenance behaviors post treatment.

As people emerge from the physical and emotional intensities of cancer treatment, they often find themselves in a world that is intimately familiar yet forever changed. Typically, few signposts exist to guide these highly personal journeys. Survivorship research cross-cuts the entire research portfolio to help chart and remediate that journey. We strive to adapt treatment to avoid chronic and late effects, ensure appropriate follow-up and post-treatment screening, prevent recurrence, and enable a high quality of life for cancer survivors and their families, friends, and caregivers.

STRATEGY 7.2—Expand the development and use of tools to assess the health-related quality of life of cancer survivors and their family members across the trajectory of care.

Improving patient outcomes will require tools to measure and describe patients' experience of illness, treatment, and recovery. NCI will:

- > Support the identification, development, and testing of instruments to assess the health-related quality of life of patients and survivors from diagnosis through the end of life.
- > Promote the routine use of standardized instruments at systematic time points across the trajectory of care, including the adoption of newly established criteria for monitoring harmful late effects of cancer treatment.
- > Collaborate with other NIH Institutes to support the development of measures and create data banks for evaluating comorbidities to better describe the effects of a cancer diagnosis on long-term health.
- > Support the development of measures to assess the impact of a patient's cancer on the health-related quality of life of family members and caregivers.



STRATEGY 7.3—Accelerate intervention research designed to reduce cancer-related acute, chronic, or late morbidity and mortality.

As we learn more about the types and causes of adverse health-related outcomes among cancer patients and survivors, it will be critical that interventions to address them keep pace with our findings. We will:

- > Advance research on the most promising and cost-effective interventions to address cancer patient and survivor needs for improved quality of life—e.g., reducing cancer-related symptoms such as distress, pain, and nausea; minimizing post treatment organ dysfunction; treating infertility; promoting healthy practices such as exercise, smoking cessation, and diet change; and addressing individual needs.
- > Support research to investigate the impact of well characterized and controlled interventions on appropriate intermediate biomarkers such as immune function, cortisol levels, and hormone levels.

- > Advance intervention development that promotes the health and well-being of family members and caregivers as well as interventions that target patients and survivors in minority and medically underserved populations.
- > Foster development of screening tools that identify individuals or families at high risk for poor outcomes and support research to assess the impact of such screening on patterns and outcomes of care including health-related quality of life.
- > Support the development of personalized treatments for individual patients based on their predisposition for adverse outcomes.

STRATEGY 7.4—Ensure that relevant audiences receive new information, interventions, and best practices for addressing the health needs of survivors and their families.

As information becomes available about the nature of and ways to improve health-related quality of life outcomes for cancer patients, survivors, and their families, we must understand how to effectively disseminate this knowledge and evaluate its impact on care. We will:

- > Support the development and dissemination of curricula and standards for delivering effective psychosocial and supportive care for cancer patients and survivors to a broad spectrum of healthcare providers and cancer professionals.
- > Collaborate with other Federal and health- or cancer-related professional and nonprofit organizations and advocacy groups to promote the development and dissemination of educational materials across diverse media platforms—e.g., written, CD, audiotape, online, telephone—for family members and healthcare providers.
- > Assess health-related information needs and resources through patient, family member, and healthcare provider surveys and use this information to guide the development of educational tools and outreach efforts.